

# Best Practice

## EVIDENCE-BASED CASE REVIEWS

### Addressing the religious and spiritual needs of dying patients

The patient is a 52-year-old man with non-Hodgkins' lymphoma diagnosed 3 years ago. He has been through several courses of chemotherapy, followed by remissions of increasingly shorter duration and increasingly burdensome toxic reactions. He has received maximal dosages of irradiation. His last 2 cycles of chemotherapy have failed to achieve a remission. He is pancytopenic and not responding to biologic stimulants. He has recurrent malignant pleural effusions and constant pain. He has been married for 16 years and has a 14-year-old son and a 12-year-old daughter. His internist has discussed the situation carefully and compassionately with the patient, who understands that he is approaching the end of his life. He tells his physician, "I can't believe God is doing this to me."

How should the patient's physician respond to his questions? The caring physician might say simply, "Sounds like you're upset." Other physicians might avoid even the psychosocial issues and steer the conversation back to more familiar clinical issues by saying, "I understand that you're upset that the last round of chemotherapy failed. Let me tell you about a new experimental drug we might try." Yet another physician might address the issue head on, using the explicitly religious language with which the patient has expressed his concerns and say, for example, "It sounds as if your illness is putting a strain on your relationship with God." I will explore the literature that might shed light on this and related clinical questions.

#### THE NATURE OF THE EVIDENCE

An evidence-based review article regarding the physician's role in addressing the religious and spiritual needs of patients at the end of life poses problems not encountered in other articles in this series. However, rather than detailing these controversies at the outset, I will integrate a discussion of them into the article. I have drawn from a limited but growing literature, using MEDLINE, BIOETHICS-LINE, books, and bibliographies. Few of these studies meet the usual criteria of evidence-based medicine. Nonetheless, questions about religion and spirituality often arise in clinical practice and need to be reviewed.

#### DO PATIENTS WANT THEIR PHYSICIANS TO ADDRESS THEIR SPIRITUAL CONCERNS?

Between 41% and 94% of patients want their physicians and nurses to address their spiritual concerns.<sup>1-6</sup> However,

physicians have generally been reluctant to do so,<sup>7</sup> do not consider spiritual concerns important,<sup>8</sup> and fail to address them in end-of-life care.<sup>9-11</sup>

In one survey, even 45% of nonreligious patients thought physicians should inquire politely about patients' spiritual needs.<sup>3</sup> Nonetheless, if patients reply that they do not have spiritual or religious concerns or do not wish them to be addressed in the context of the patient-physician relationship, the physician must respect their refusal to engage such questions.

#### SPIRITUALITY AND RELIGION

In pluralistic health care settings, clinicians should distinguish between spirituality and religion.<sup>12</sup> Some will describe themselves as "spiritual" though not religious. Spirituality refers to an individual or a group's relationship with the transcendent, however that may be construed.<sup>13</sup> Religion, by contrast, is a set of beliefs, practices, and language that characterizes a community that is searching for transcendent meaning in a particular way, generally based on belief in a deity. Thus, although not everyone has a religion, everyone who searches for ultimate or transcendent meaning can be said to have a spirituality.

#### CAN THE EFFECTIVENESS OF INTERVENTIONS THAT ADDRESS THE SPIRITUAL CONCERNS OF PATIENTS BE MEASURED?

The idea of measuring spiritual awareness, spiritual need, spiritual distress, or religious coping poses several theologic questions.<sup>14</sup> For example, one might ask whether it is conceptually possible to quantify transcendence without being inconsistent—trying to quantify the nonquantifiable. Nonetheless, patients and researchers can identify particular aspects of human distress, ways of coping, and particular behaviors as religious or spiritual. And these attitudes, beliefs, feelings, and behaviors are amenable to measurement. As long as it is understood that these measurements give an extremely limited view of the spiritual life, these tools have their place.

#### WHAT DOMAINS MIGHT BE MEASURED?

I suggest the following 4 distinct categories of spiritual measures: religiosity, spiritual coping, spiritual well-being, and spiritual need.

##### Religiosity

Religiosity concerns the behaviors and attitudes a person has with respect to a particular religion. Measurable items include behaviors such as church attendance, prayer, the reading of sacred texts, and attitudes, such as strength of religious belief.<sup>15-19</sup> Many studies have linked religiosity to

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improved long-term health outcomes.<sup>15-18</sup> There is little information about linkages between religiosity and end-of-life care. Nonetheless, it would seem sensible to inquire about Mr Jones' previous religious practices, even though it cannot be said that this is based on any firm "evidence."

### Religious coping

Religious coping refers to how a person's religious beliefs, attitudes, and practices affect his or her reaction to stressful life events.<sup>19,20</sup> It is relevant to the care of a dying patient to assess what inner resources the patient has for dealing with the stress of terminal illness. For example, Mr Jones might have worshipped at church services weekly for almost all of his life but might be thinking now that God is punishing him for some past sin.

### Spiritual well-being

The World Health Organization has declared that spirituality is an important dimension of quality of life.<sup>21</sup> How

someone is faring spiritually affects that person's physical, psychological, and interpersonal states—and vice versa. All contribute to overall quality of life. Thus, it is particularly useful to try to measure spiritual well-being or its opposite, spiritual distress. Many instruments are now available.<sup>22-28</sup> Some of these instruments have been criticized as confounding spiritual well-being with psychological well-being,<sup>29</sup> but all of them have their pros and cons. Excellent reviews have been prepared by Mytko and Knight<sup>30</sup> and Puchalski.<sup>31</sup> Clinicians who care for patients at the end of life need to be especially aware that the relationship each patient has with the transcendent is an important component of the quality of that patient's living and dying.

### Spiritual needs

Qualitative studies have suggested that patients have many spiritual needs.<sup>32</sup> Unfortunately, there are few available instruments.<sup>4,33</sup> So, although it may seem obvious when Mr Jones asks, "Why is God doing this to me?" that he is expressing spiritual needs, physicians have few clinical tools at their disposal to assess more precisely what those needs might be. Physicians should be aware that dying patients may have unmet spiritual needs that they have not spontaneously expressed to health professionals. To facilitate meeting those needs, we must be aware of what they are.

### IS THERE ANY EVIDENCE THAT SPIRITUAL INTERVENTIONS BY PHYSICIANS HELP DYING PATIENTS?

There are almost no data regarding the "effectiveness" of spiritual interventions. One survey of relatives of deceased patients showed that 63% thought that their loved one's faith was of help at the time of death.<sup>34</sup> There is one randomized controlled trial underway to test the integration of attention to spiritual issues into the psychotherapeutic care of patients with cancer.<sup>35</sup>

Several studies have investigated the "effectiveness" of prayer at a distance.<sup>36,37</sup> These studies have evoked both methodologic and theologic criticism.<sup>38,39</sup> For example, the scales measuring efficacy have not been validated and vary from study to study. Religious critics wonder why God, in answering prayers, would decrease the incidence of Swan-Ganz catheters but not decrease mortality, and they worry about the theologic implications of treating prayer like a therapeutic nostrum. Space considerations preclude a full discussion of these controversies.

### SHOULD IT BE DONE AT ALL?

It remains controversial whether physicians should attempt to address the spiritual needs of patients, even at the end of life.<sup>40-42</sup> Critics fear inappropriate proselytizing of



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Is it possible for physicians to quantify transcendence?

patients or the replacement of well-established, scientific western medicine with quackery. Both of these types of concerns are well placed. Proselytizing and quackery can do severe harm to patients. However, the approach advocated by responsible proponents of physician involvement in spirituality and end-of-life care avoids both of these pitfalls.<sup>12,43</sup> Medicine ought to eschew both proselytizing and quackery, but this does not imply that they ignore the genuine spiritual concerns raised by patients. Those with the greatest experience in caring for the needs of the terminally ill, hospice and palliative care workers, have always attended to the spiritual needs of patients and may provide a model.<sup>44-46</sup>

It has been suggested that addressing patients' spirituality is warranted because it is associated with clinical outcomes and patient coping, because patients want it, and because it can affect their decision making.<sup>47</sup> But perhaps the main reason for addressing the spiritual concerns of patients at the end of life is that these concerns affect them as whole persons and in their overall sense of well-being.<sup>14,48</sup> To ignore these concerns at the end of life is to remove from the patient-physician interaction an important component of the patient's well-being precisely at the time when standard medical approaches have lost their curative or even life-sustaining efficacy.

## HOW MIGHT PHYSICIANS ADDRESS SPIRITUAL NEEDS OF PATIENTS AT THE END OF LIFE?

Spiritual issues, such as questions about meaning and value, arise naturally in the dying process.<sup>14</sup> But how can physicians address these questions with patients? First, they can begin to learn to pay attention to patients' clues. When Mr Jones asks, "Why is God doing this to me?" he is probably struggling with questions of value and meaning in the context of his relationship with God. Simple communication techniques such as reflecting the patient's own words back work well—for example, "It sounds as if you are really questioning why God is doing this to you." Other clues may be more subtle. For example, a set of rosary beads or Shabbat candles or a copy of the Koran lying on the table next to the patient's bed may be there to invite inquiry.<sup>13</sup> Simply acknowledging that they are there may be sufficient to "break the ice" with the patient.

Second, pay attention to the importance of the physician-patient relationship as a possible context for the patient to work through and express spiritual concerns and struggles. For example, a request for chemotherapy might actually represent a fear of losing a relationship with an empathetic oncologist.<sup>49</sup>

Third, pay attention to the spiritual lessons that the dying can teach.<sup>14</sup> As MacIntyre has noted, the dying can help physicians to learn that all persons, including physicians, are vulnerable and ultimately dependent on oth-

ers.<sup>50</sup> The dying have this role, even when they have become otherwise "unproductive."

Fourth, physicians need to pay attention to their own spiritual histories and to be conscious of how this affects the care they give their patients.<sup>48</sup> This is especially true in caring for patients at the end of life.<sup>51,52</sup> For instance, a physician's own intense personal desire for control may make it difficult to help a religious patient to accept control by God at the time of death.

Fifth, physicians should begin to take spiritual histories. Several helpful acronym-lists have been recommended as aids for those who are inexperienced.<sup>12,43,47,53,54</sup> All are strikingly similar, even though they have been developed independently. Relevant topics include inquiry about sources of hope, actual beliefs, personal practices, integration in a religious community, rituals, and importance in health care decisions. I tend to begin by asking a simple open-ended question, "What role does spirituality or religion play in your life?"

When the patient brings the issues up, the physician should always acknowledge the spiritual concerns raised by the patient, respond to the patient, listen respectfully, and refer to pastoral or spiritual care when appropriate (box). In the case of Mr Jones, the physician might say, "It sounds as if your illness is putting a strain on your relationship with God." This acknowledges the importance of the question to the patient, prevents it from becoming redirected into biomedical concerns, and implies responsiveness and a willingness to listen.

### Responding to patient clues about spiritual concerns

**Acknowledge** Do not ignore the clues, whether verbal or nonverbal, but acknowledge that you have noticed the concern. For example, simply ask, "Is that the Koran you're reading?"

**Respond** Acknowledging that the patient has expressed spiritual concerns is necessary but not sufficient. Sometimes this acknowledgment will also be an invitation for the patient to "open up" and share more spontaneously. If not, it may be necessary to ask explicitly—for example, "Would you like to speak more with me or a chaplain about your spiritual concerns?"

**Listen** Avoid the temptation to provide answers, even if the patient is of your own religious background. The most important task for the clinician is to elicit spiritual concerns, and this is best achieved by listening respectfully and attentively.

**Refer** Having elicited the patient's spiritual concerns and having reassured the patient that these are "safe" topics for discussion in the context of the physician-patient relationship, make arrangements for referral if important issues remain unresolved after a brief discussion. Appropriate referrals include suggesting that the patient pursue the matter further with his or her clergy or make a referral to the hospital's pastoral or spiritual care department.



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Spirituality is an important dimension of quality of life

In reply, Mr Jones might spontaneously disclose that he is a regular churchgoing Baptist, that his faith is genuinely being tested, that his family is praying for him as is his church, and that he feels most troubled by the fact that his son can't accept that his father might die soon of lymphoma. Having heard this, the physician might ask, "Have you spoken with your pastor about your concerns?" The patient might then

acknowledge that he had thought about it but had procrastinated, based on "stubborn male pride." But he might acknowledge that this was a good idea and might thank the physician for helping him to take a step toward doing what he already knew was right for him.

### ARE THERE LIMITS TO PHYSICIAN INVOLVEMENT IN THE SPIRITUAL CONCERNS OF PATIENTS AT THE END OF LIFE?

Some physicians may justifiably fear initiating conversations about end-of-life care because they are unsure where this involvement might take them. Paying attention to the spiritual needs of patients does not require physicians to assume the role of pastor or guru. Physicians also need to acknowledge the limits of their expertise and to refer to those trained to provide spiritual care, especially those trained through rigorous programs of clinical pastoral education.<sup>47(p52),55</sup>

Whether (and if so, when and how) physicians should pray with their dying patients is a matter beyond the scope of the present review. Although many believe there are situations that call for such prayer, not all patients and not all physicians will find this comfortable. Nonetheless, it seems relatively uncontroversial that physicians should feel free to pray for their patients privately, which would avoid any hint of proselytizing.<sup>12</sup> And even physicians who are not themselves religious can acknowledge and be sensitive to the spiritual dimensions of their work.<sup>48</sup>



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